

**386 End of life care for people with cystic fibrosis (CF)**

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**Objectives:** To gauge the need, understanding and wish to discuss Palliative Care (PC) and/or End of Life Care directive for PWCF with CF teams and/or family. To give PWCF the forum to discuss end of life care EOLC/PC if they so wish. To research best practices in our CF centres for EOLC/PC involvement. To support CF teams in any way possible through awareness and education on issues surrounding EOLC if needed.

**Method:** This is an ongoing project; to date,

- Meetings have been held with representative from the CFAI, Irish Hospice Foundation (IHF), CF Multidisciplinary Teams and CF Patient Advocate.
- PWCF patient group held a teleconference meeting to discuss EOLC.
- A questionnaire was developed and sent to CF centres to ask for their opinion and policies on EOLC.
- A draft discussion paper for PWCF, CF families, and CF teams is available for comment.
- A poster has been devised in conjunction with the IHF as a starting block for further research and education on EOLC/PC for PWCF.

**Conclusion:** Doing this research has opened the doorway for discussion between CF teams, CFAI and patient groups. For PWCF it gives freedom to discuss EOLC issues freely with one another. The feedback received from the multidisciplinary teams to date will result in a stepping stone to support literature being developed for healthcare professionals caring for PWCF. Further discussions with psychologists working on CF multidisciplinary teams, with the aim of producing information leaflets on the issues surrounding EOLC. We have produced a poster which identifies the main areas we need to develop as an association.

**387 Validation of the Spanish version of the Leicester Cough Questionnaire in children with cystic fibrosis**

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**Introduction:** The respiratory system of cystic fibrosis (CF) patients presents chronic inflammation with a thickness of the mucus and decrease of the ciliar mobility. Causing, between many manifestations, chronic cough that affects quality of life and social relations.

**Objective:** Validate the Spanish version of the Leicester Cough Questionnaire (LCQ) in a population of CF children.

**Methods:** After the adaptation to Spanish, the sample was formed by patients between 7 and 18 years old, with a total of 58 individuals, from Corporación Parc Taulí (Sabadell) and Asociación Madrileña Contra la Fibrosis Quística (Madrid) in Spain. The questionnaire was administered twice in stable disease patients in order to contrast the results.

**Results:** The population was composed by 62% male and 38% female, with a medium (SD) age of 11.7 (3.1) and BMI of 19 (13). The total values were LCQ<sub>1</sub> 18.46 (2.4) vs LCQ<sub>2</sub> 18.69 (2.3) ( $p=0.769$ ). The Cronbach's alpha coefficients was 0.86 LCQ<sub>total</sub>; 0.76 LCQ<sub>physical</sub>; 0.79 LCQ<sub>psychological</sub> and 0.78 LCQ<sub>social</sub>. The intraclass correlation coefficients was LCQ<sub>physical</sub> 0.82 ( $p<0.01$ ), LCQ<sub>psychological</sub> 0.75 ( $p<0.01$ ), LCQ<sub>social</sub> 0.63 ( $p<0.01$ ) and LCQ<sub>total</sub> 0.83 ( $p<0.01$ ). The relations with the CF quality of life questionnaire shows a relation of  $r=0.51$  ( $p<0.01$ ) with the respiratory symptoms domain for the child version and  $r=0.67$  ( $p<0.05$ ) for the same domain for teenagers. Also, there were relations between the LCQ and the pulmonary function like FVC (LCQ<sub>physical</sub> 0.42,  $p<0.01$ ; LCQ<sub>psychological</sub>  $r=0.60$ ,  $p<0.01$ ; LCQ<sub>social</sub>  $r=0.46$ ,  $p<0.01$  and LCQ<sub>total</sub>  $r=0.55$  with an  $p<0.01$ ).

**Conclusion:** The Spanish version of the LCQ is reliable and valid to CF patients.